

## **An Act Expanding Health Insurance Coverage of Specialized Formula for Children with Eosinophilic Disorders**

### **Insurance and Real Estate Committee**

**February 19, 2013**

Hi. My name is Stephanie Billiel. I'm here today to speak in support of House Bill 5432 to expand coverage of medical food for people with Eosinophilic Gastrointestinal Disorders, also known as EGID, and for FPIES.

EGID is a genetic disease, and several of my family members are affected. My husband has a mild form. He's lucky that his symptoms are controlled with daily medication. My sister-in-law requires medication and dietary restrictions to control her EGID. As is the case with most EGID patients, they do not take medical food. My older son, Caleb, has the most severe case in the family. He requires a combination of medications and a strict diet of nothing but medical food to control his EGID. He drinks some of the medical food formula, and the rest he takes through a feeding tube.

Caleb was born weighing 9 pounds, 7 ounces and measuring 22 inches long. He was a big boy, and he stayed that way until he started to eat solid foods. Once he started solids, he became increasingly ill with vomiting, alternating diarrhea and constipation, choking episodes, a chronic cough, difficulty swallowing, and dysfunction of his GI tract that caused an obstruction and bleeding in his bowel. His development regressed, and he went from speaking in sentences at an early age to using single words. He didn't have energy to play and spent days just lying on the couch. My big boy was literally starving to death.

The medical bills piled up. There were visits to the family doctor and to specialists and medical tests were ordered. As his condition deteriorated, Caleb had 4 emergency department visits and 2 admissions in just a few weeks' time. Finally, he became so ill that he was admitted to the hospital for 8 days. He could no longer eat and was given a feeding tube. The gastroenterologist treating Caleb in the hospital suspected EGID and ordered Neocate Junior, a type of medical food, to feed him through the tube. The diagnosis of EGID was confirmed a few days later via an endoscopy with biopsies.

In the past 2 years since Caleb's diagnosis, he has not needed a single emergency department visit thanks to the preventative care provided by medical food.

Perhaps you are worried about cost of expanding medical food coverage. If so, I want to caution you that you should be much more concerned about the cost of NOT covering medical food for these children. Withholding medical food from people with severe EGID causes serious, expensive health issues. As you can see from my son's story, in just a few weeks of a severe EGID flare, our insurance paid out enough in avoidable medical expenses to cover the cost of his medical food for several years. Not only is covering medical food the right thing to do; it makes financial sense for everyone involved – the families affected, the insurance companies, and the State.

Thank you for your time. Are there any questions?